



RI-NEDSS POLICIES & PROTOCOLS

**RI Department of Health
Center for Epidemiology**

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Approved by:

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RI-NEDSS Policies and Protocols

Surveillance Case management of Patient Information in NEDSS

The NEDSS (National Electronic Disease Surveillance System) is a web based application that serves as a tool for improving surveillance for reportable diseases. A primary goal of NEDSS is the ongoing manual and automatic capture and analysis of reportable disease data. It gives users the ability to enter, manage and view core demographic and clinical disease data, transmit data and produce epidemiologic reports for public health action.

In RI, diseases are coded as Black (4 day reporting), and Blue or Red (24 hour reportables) according to the “RI Reportable Diseases Summary Sheet for Clinical Providers” that is available at <http://www.health.ri.gov/disease/communicable/summarysheet.pdf>

These policies apply to NEDSS reportable conditions only. Currently TB, STDs, HIV/AIDS, Influenza and Varicella are not part of NEDSS. In addition VRE is exempt from NEDSS reporting. Out of State reports are also exempt.

Staff indicated in parenthesis are responsible for the function(s) described. The most current disease-specific staff assignments as maintained by the Office will be provided in a separate list for reference.

Staff assignments will be provided as a separate list for reference and these policies will apply to the most current list as maintained by the Office.

In addition to individual mail boxes, paper documents will be managed using the following NEDSS specific bin system:

1. All incoming mail/fax reportable conditions.
 2. Reports to clerical for registration.
 3. Reports registered in NEDSS.
 4. Reports completed in NEDSS for filing.
 5. Reports for general filing.
 6. Not a Case file.
 7. Out of State reports
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1. **Timeline for registering cases into NEDSS** (*Center for Epidemiology Nurses, Disease Intervention Specialists, Clerical Staff*).
 - 1.1. Registering a condition is defined as entering the required fields into the basic NEDSS demographic page.
 - 1.2. **Black** coded diseases: The timeline for registering a condition is within **2 working days** of receipt of the report by the Office.
 - 1.3. **Red** and **Blue** coded conditions are required to be registered into NEDSS within 24 hours of receipt by the Office.

- 1.4. Animal bites and vectorborne diseases (Ehrlichia/Babesia/Lyme/RMSF/malaria) must be registered within 1 month.

2. Timeline for managing cases through to completion in NEDSS.

- 2.1. Completion of a case is defined as creating an investigation, case managing all aspects of the case, closing an investigation, assigning a case classification and creating a notification.
- 2.2. **Black coded** conditions--- The timeline for this activity is **2weeks** from the day the case is registered in NEDSS.
- 2.3. Exceptions to the two-week completion time frame include:
 - **Conditions that require a hospital chart review for completion - within 3 months of notification to HEALTH.**
 - Encephalitis
 - H. influenzae disease
 - Hemolytic Uremic Syndrome
 - Pneumococcal disease
 - Meningitis/Bacteremia
 - Toxic Shock Syndrome
 - Group A Strep
 - Group B Strep

Complete chart reviews and case manage in the NEDSS system to completion via Notification or Closed Investigation within 3 months of notification to HEALTH.

- **Chronic Hepatitis B, and C-** register as per Section 1.1 above and hold for follow-up labs
 - **Any conditions requiring detailed investigation with patient and/or provider interviews – to be completed within 2 months of notification to HEALTH** e.g. Animal bites, PFGE clusters, vectorborne diseases .
- 2.4. If it is not possible to enter the basic demographic information within the time frame specified in 1.1 and 1.2 notify the State Epidemiologist and the Chief of the Center for Epidemiology who will decide how to handle the case. Also all exceptions and delays must be communicated by e mail to the Chief and State Epidemiologist.

3. Registering Reported Cases of Notifiable Disease.

3.1. Responsibilities of the Nurse On-Call

3.1.1. Black Coded Reportable Diseases:

- 3.1.1.1. Review all faxed reports and in-coming mail and registered reports (i.e. bin 1 and bin 3) that pertain to the reporting of a disease.
- 3.1.1.2. On-call nurse sorts above reports from bin 1 and bin 3 to staff mailboxes based on assignments (these may be registered or prior to registration reports.)

3.1.2. Special Instructions for *Red* and *Blue* Coded Disease Reports

3.1.2.1. Reports received by fax or mail

Hand-deliver faxed or mailed in reports of *red* or *blue* coded diseases to the assigned Nurse/Disease Intervention Specialist unless specifically directed to hand report to State Epidemiologist directly. The Nurse/Disease Intervention Specialist will then register and case-manage the condition in NEDSS in consultation with the State Epidemiologist. If the assigned Nurse/Disease Intervention Specialist is out of the office, the paperwork will be handed to the State Epidemiologist, or Chief of the Office.

3.1.2.2. Reports Received by Phone:

Receive and complete "Telephone Disease Intake Form" for cases of reported priority diseases triaged via phone from the front office. Hand-deliver "Telephone Disease Intake Forms" to the assigned Nurse/Disease Intervention Specialist unless specifically directed to hand report to State Epidemiologist directly. The Nurse/Disease Intervention Specialist will then register and case-manage the condition in NEDSS in consultation with the State Epidemiologist. If the assigned Nurse/Disease Intervention Specialist is out of the office, the paperwork will be handed to the State Epidemiologist, Office Administrator, or Chief of the Office for assignment.

3.1.3. Responsibilities of the Nurses/Disease Intervention Specialists

3.1.3.1. Review reports in personal mailbox and process as:

- 3.1.3.1.1. For Reports already registered in NEDSS – case manage through the NEDSS system within the time specified (Section 1)
- 3.1.3.1.1.1. For Reports not registered in NEDSS process as:
 - 3.1.3.1.1.1.1. Reportable disease case - Place in bin to be registered by clerical staff (bin 2).
 - 3.1.3.1.1.1.2. Not A Case reports are to be placed in Not a Case bin to be reviewed by State Epidemiologist
 - 3.1.3.1.1.1.3. Out of State case to be placed in bin for Out of State Reports bin,

3.1.3.1.1.1.4. General File bin is for paperwork that does not fit above categories.

3.1.3.1.1.1.5. If unable to interpret lab report (for example *gram negative rods*) bring to the attention of State Epidemiologist immediately.

3.1.3.2. Register and case-manage assigned Red and Blue coded reportable diseases.

3.1.3.3. Receive phone reports of cases pertaining to assigned diseases and process for case management as above in. 2.1.3.1.1.1

When all work is complete place paper records in bin 4 (**reports completed in NEDSS for filing**).

3.1.4. Responsibilities of Designated Clerical Staff

3.1.4.1. Receive cases of reportable diseases other than the red and blue diseases from nurses/disease intervention specialists (bin 2).

3.1.4.2. Register disease reports into the NEDSS system.

3.1.4.2.1. Search the NEDSS system to see if the patient already exists in the system. If the patient exists review the new record with what already exists and make the necessary changes by editing the record for that date.

3.1.4.2.2. If the patient does not exist in the NEDSS system, ADD the patient and the demographic information for the date specified on the report. All cases of reportable diseases other than the red and blue diseases will be registered in the NEDSS system by the clerical staff.

3.1.4.2.3. Review record for completeness of required demographic fields and make calls as needed* to acquire the necessary required information for the demographics.

3.1.4.2.4. Place registered forms in bin 3 (reports registered in NEDSS)

3.1.4.2.5. Maintain filing system for bin 4 - Reports completed in NEDSS for filing, bin 6 - Not a Case file, bin 7 - Out of State reports, and bin 8 - Reports for general filing.

3.2. Instructions for Reports Received that are Non-Cases (*Center for Epidemiology Nurses, Disease Intervention Specialists*)

3.2.1. Laboratory/Morbidity Reports Received via Mail or Fax that are not Cases

If a Laboratory or Morbidity report received by the Center for Epidemiology is a questionable case the report will be placed in the bin for the State Epidemiologist to review. If the State Epidemiologist agrees that the report will not be considered a case it will not be entered into NEDSS. A hard copy of the report will be placed in a file for reports that are not cases. If the State Epidemiologist considers the report to warrant an investigation, then an investigation will be created and case-managed through to completion by the assigned Nurse or DIS as described in Section 2.

3.2.2. Laboratory/Morbidity Reports Received via Electronic Laboratory Reporting (ELR) that will not be considered a case

A lab report or morbidity report that is directly transferred into NEDSS via ELR, will appear in the *Observation Needing Review* queue. If a report is questionable as to whether or not it is to be considered a case, notify the State Epidemiologist by e mail to review the report or print the report and give it to the State Epidemiologist. If the State Epidemiologist determines that the report is not a case, **Mark as Reviewed**. These reports will not need further action and will not be considered a reportable case.

4. Case Managing Patient Records (*Center for Epidemiology Nurses, Disease Intervention Specialists-for assigned conditions*)

4.1. Initial Check for Assigned Conditions

4.1.1. The *Observations Needing Review* queue found on the NEDSS homepage will be checked 3-4 times during the day for assigned conditions and priority given to assigned conditions that have an **IMMEDIATE** reporting status such as the **Blue** and **Red** conditions.

4.1.2. The *Observations Needing Review* checking time is to be spread over several hours to cover the a.m. and p.m. hours. Special attention should be given to checking for those conditions that have an **IMMEDIATE** reporting mandate such as Hepatitis A, meningococcal disease, Encephalitis (see RI notifiable diseases)

4.2. Review of Conditions

4.2.1. Any observation for assigned conditions that clearly will not result in a notification or does not meet the case reportable status for RI reportable conditions or does not need to have more information added is to be **“Marked as Reviewed”**. See Section 2.2 above for reviewing with State Epidemiologist before **marking as reviewed**.

4.2.2. If a condition needs to be worked on further to determine case status and/or to create a notification then **“Create an Investigation”**.

4.3. Managing the Investigation

- 4.3.1. Investigations are created by the person who is assigned to that particular condition (Section 3.2.2).
- 4.3.2. The status of an investigation is to remain OPEN until all the necessary information has been entered. Once all the required information is entered the investigation must be **CLOSED** and a **NOTIFICATION** created for the State Epidemiologist (or proxy) to review.
- 4.3.3. The Investigation queue needs to be checked daily for Open Investigations.
- 4.3.4. All OPEN Investigations remain in the Investigation queue. OPEN Investigations that are older than two (2) weeks except as specified in section 1 above will be reviewed.

4.4. **Notification Creation**

- 4.4.1. Notifications are to be created for all completed investigations that meet the case definition for that particular condition.
- 4.4.2. The notification is created following the closure of an Investigation. The notification is sent to the State Epidemiologist or proxy who will review the case and release the report to CDC if it meets the case definition. If the notification needs more information or edits, the rejected notification will show up in the Rejected Notification queue on the homepage. The reason for rejection and edits to be made will be found in that queue.
- 4.4.3. Once a notification has been created, the investigator will initial, date, and place any attending lab or morbidity reports for the closed investigation in the State Epidemiologists file designated specifically for that purpose.

5. **Editing, Updating, Deleting, and Merging Patient Records** (*Center for Epidemiology Nurses, Disease Intervention Specialists, Epidemiologists, Designated Clerical Staff, Administrator*)

- 5.1. **Editing and Updating** case records is the responsibility of the person who is assigned to case-manage specific conditions and to designated clerical staff who are entering demographic information into the NEDSS system. Editing and Updating a record is defined as changing a field in a record, deleting a field from a record, adding new information to a record, or updating a record. For deleting an entire record see Section 4.2.
- 5.2. **Deleting Records**
The decision to delete a record is the responsibility of the NEDSS Administrator in collaboration with the assigned Epidemiologist. The NEDSS Administrator will maintain a log of all deleted records
- 5.3. **Merging of Records**

Checking for duplicates and merging of records is the responsibility of the NEDSS administrator.

6. Entering Facility Information (*anyone who enters data into the NEDSS system*)

Several entries exist for many of the clinical laboratories depending on the location of the lab that is sending the report (i.e. Quest, East Side Clinical have many stick labs). The main laboratory is to be entered when entering Facility Name Information.

7. Managing Electronic Laboratory Reports (ELR) (*Center for Epidemiology Nurses, Disease Intervention Specialists, Nurse(s) On-Call*)

- 7.1. **Electronic Laboratory Reports are viewed from the *Observations Needing Review* queue.** Search (alphabetically) for the conditions that you are assigned AND view each Electronic Laboratory Report. For each report determine if the condition being reported is likely to be a case that will be reported to CDC.
- 7.2. If the condition reported is clearly “NOT A CASE” then mark the report as reviewed (click on **Mark as Reviewed** button in upper left of screen). It will disappear from the Observation queue and nothing more needs to be done with this case.
- 7.3. If it seems likely that the condition will result in a notification then create an investigation and complete the required fields for that condition (required fields are given for each condition on the Condition Specific Definition Sheets). After the investigation is complete, create a NOTIFICATION and send it to State Epidemiologist or proxy.

8. Protocol for Laptops for Chart Reviews (*Center for Epidemiology Nurses who are responsible for hospital chart reviews*)

- 8.1. There will be 2 laptops available for performing chart reviews at local hospitals. Laptops will allow NEDSS access in the hospital and direct chart to NEDSS data entry can be done.
- 8.2. Laptops will be housed within the Center for Epidemiology and will be issued upon request.
- 8.3. Laptops can be signed out by completing a request form that asks for the date you will be using the laptop, the date you will be returning the laptop, the reason for the request and your signature.
- 8.4. Laptops may not be left in cars overnight. They must be returned to the office at the end of the requested sign-in date.

9. Notifiable Conditions for Out of State Persons (*Center for Epidemiology Nurses, Disease Intervention Specialists*) Out of State Reports on Notifiable Conditions for non-RI residents will be maintained as a paper trail. These conditions are not to be entered into the NEDSS system. If reports arrive via ELR, mark as Reviewed, print out a copy and file for review by State Epidemiologist and interstate reciprocal notification.

10. LDF Protocol (*Center Epidemiologists, NEDSS Administrator*)

- 10.1. Center Epidemiologists are responsible for updating and maintaining LDFs for their assigned conditions except as specified by the CSC NEDSS ASP Standard Operating Procedure that states that LDFs needing codesets must go through CSC via NEDSS Administrator. Updated or new LDFs will be set up and tested on the Staging Server before being transferred to the Production or Live Server.
- 10.2. When LDFs are updated, edited, or created, the appropriate Data Definition Sheets will be updated by the Center Epidemiologist responsible for revising the LDF and sent to the NEDSS Administrator noting the date and description of the change. The NEDSS Administrator will be responsible for updating the master LDF Excel database and for notifying NEDSS users of updated items.

11. Review of Disease Conditions within the NEDSS system (*Center Epidemiologists*)

- 11.1. Epidemiologists will review disease conditions and specific epidemiology reports every 2 months.
- 11.2. Epidemiologists will meet with the State Epidemiologist at least every 2 months to discuss the data quality for disease conditions being entered into NEDSS and make recommendations for improving surveillance systems.
- 11.3. Epidemiologists will generate status reports on their specific diseases for the State Epidemiologist and Center Chief.
- 11.4. Epidemiologists will monitor closed investigations weekly for their conditions.

12. Epidemiology Reports (*Center Epidemiologists*)

- 12.1. **Requests for Data.** Requests for data come from a variety of sources and through a variety of channels: phone, e-mail, letter.
 - 12.1.1. Requests for Data are to be submitted by completing the “Standard Data Request Form”.
 - 12.1.2. All data requests received by any staff or by persons external to HEALTH must be channeled to the Epidemiologist responsible for that condition.
 - 12.1.3. The Epidemiologist will seek direction from the State Epidemiologist prior to responding to the request.
 - 12.1.4. Responses to data requests will be recorded on a log to be maintained by the epidemiologist; this log will be reviewed periodically to inform NEDSS improvement projects.
- 12.2. **Routine Reports**
 - 12.2.1. Epidemiologists are responsible for creating reports on their assigned diseases as requested by the State Epidemiologist.

- 12.2.2. Epidemiologists are responsible for creating yearly aggregate reports for their assigned diseases that are posted to the website.

13. Administrative Reports (*NEDSS Administrator*)

- 13.1. The NEDSS Administrator will generate system reports.
- 13.2. The following reports will be generated biweekly:
 - 13.2.1. Number of Observations needing review
 - 13.2.2. Number of Notifications Sent to CDC
 - 13.2.3. Number of pending Notifications
 - 13.2.4. Line List of merged and deleted documents
 - 13.2.5. Summary of Cases Entered into the NEDSS to date
 - 13.2.6. Summary of Cases by Investigator
 - 13.2.7. Other reports as requested by management
 - 13.2.8. Summary of System reports will be sent to Office Chief and State Epidemiologist monthly.

14. Protocol for System Down Time (*Everyone*)

- 14.1. If down time is known as in the case of scheduled maintenance then notification will be given to all NEDSS users by the NEDSS Administrator, Office Chief or State Epidemiologist.
- 14.2. During those times when the System is down and NEDSS is not accessible, case management will continue on paper for those cases where paper reporting is available and/or the State Epidemiologist requests.
- 14.3. As soon as the NEDSS system is accessible, the person will transfer information on paper-managed cases into the system assigned to case-manage that condition.

15. Responsibilities of Center for Epidemiology Staff (*back-up person*)

- 15.1. **Center for Epidemiology Associate Director (*Center Chief*)**
 - 15.1.1. Set Policy
 - 15.1.2. Answer questions and inquires on interpretation of policy
- 15.2. **State Epidemiologist (*Center Epidemiologists*)**
 - 15.2.1. Supervise the design, implementation, evaluation and improvement of disease specific surveillance systems.
 - 15.2.2. Set Policy
 - 15.2.3. Manage all clinical areas of the NEDSS data.
 - 15.2.4. Review Notifications
 - 15.2.5. Release Notifications to CDC
 - 15.2.6. Assign disease specific conditions to staff
 - 15.2.7. Review conditions that are or will be classified as non-cases. Manage disease specific conditions with assigned staff
 - 15.2.8. Notify staff when Notification needs revising
 - 15.2.9. Coordinate and manage all workflow issues with the Chief of the Center for Epidemiology and with the Associate Director.

- 15.2.10. Oversee bimonthly meetings with Epidemiologists providing consultation and advice.
- 15.2.11. Monitor requests for data and advise Epidemiologists on responses to data requests.
- 15.2.12. Manage data flow and report generation from Epidemiologists
- 15.2.13. Review Management System Reports and work with Epidemiologists and Administrators on any issues presented in the system reports.
- 15.3. **Chief Center for Epidemiology (*Associate Director of Center for Epidemiology*)**
 - 15.3.1. Coordinate NEDSS Administrator and Project Manager on all aspects related to the NEDSS project.
 - 15.3.2. Review workload of conditions being entered and managed into NEDSS
 - 15.3.3. Coordinate and manage all workflow issues as they relate to the NEDSS project with input from State Epidemiologist.
 - 15.3.4. Inform staff of any changes related to policy issues made by the NEDSS Management Team.
 - 15.3.5. Set NEDSS policy in coordination with the Associate Director of the Office for Epidemiology and the State Epidemiologist.
 - 15.3.6. Review Management System Reports and work with Epidemiologists and Administrators on any issues presented in the system reports.
- 15.4. **Center for Epidemiology Nurses & Disease Intervention Specialists (*per standard protocol*)**
 - 15.4.1. Case Manage Assigned Conditions within the NEDSS framework and within the timeframe defined by the current Policy and Procedures manual.
 - 15.4.2. Close Investigations when complete and create notification on assigned conditions meeting the case definition.
 - 15.4.3. Review and Manage Assigned Observations.
 - 15.4.4. Notify Center Chief and State Epidemiologist when work exceeds capability of adhering to policy.
 - 15.4.5. Track assigned conditions that are OPEN.
 - 15.4.6. Edit investigations and reports as new or updated information becomes available.
- 15.5. **Epidemiologist (*other Epidemiologists in the Center*)**
 - 15.5.1. Design, implement, evaluate and recommend improvements/changes to assigned disease specific surveillance systems.
 - 15.5.2. Run routine reports related to assigned conditions.
 - 15.5.3. Review NEDSS Events bimonthly for accuracy and completeness and submit status report to State Epidemiologist.
 - 15.5.4. Collaborate with NEDSS Administrator on deletions and merging of records.
 - 15.5.5. Interact with Nurses and Disease Reps regarding the technical and clinical information for assigned conditions.
 - 15.5.6. Review and edit Definition Sheets for Correctness and Accuracy.
 - 15.5.7. Update Definition Sheets for Nurses and Disease Reps as new information becomes available or is revised.

- 15.5.8. Submit revised definition sheets to system Administrator for tracking and posting on Web
- 15.5.9. LDF management
 - 15.5.9.1. Revise LDFs as needed.
 - 15.5.9.2. Set up and test LDF on Staging Server
 - 15.5.9.3. Update Definitions Sheets for LDFs changes
 - 15.5.9.4. Transmit all LDF changes to Data Registry Manager
- 15.5.10. Submit data summary reports yearly to be posted on the Website.
- 15.5.11. Track Internal and External requests for Data
- 15.5.12. Create and submit reports on assigned conditions as requested.

15.6. **NEDSS Administrator**

- 15.6.1. Manage database including deleting records, merging records, setting and revising permissions, adding new users, removing users and tracking all changes to the system from the Center for Epidemiology
- 15.6.2. Designated State representative for CSC hosting vendor.
- 15.6.3. Manage and track all documents related to the NEDSS
- 15.6.4. Manage and Maintain website for all documents
- 15.6.5. Training including training new users and periodic training for established users.
- 15.6.6. Maintain all training documentation.
- 15.6.7. Troubleshoot problem areas.
- 15.6.8. Prepare RI Specific Training manual.
- 15.6.9. Update staff on all changes in the NEDSS system that affects data management in the NEDSS.
- 15.6.10. Prepare RI Specific QA manual for NEDSS
- 15.6.11. Generate and distribute NEDSS Management and System reports.
- 15.6.12. Prepare and Distribute monthly status reports for the Associate Director, State Epidemiologist, and Center Chief.
- 15.6.13. Track all Non-Conformance Issues.
- 15.6.14. Determine appropriate course of action to resolve data discrepancies.